



General Assembly

February Session, 2022

Substitute Bill No. 5260



AN ACT ESTABLISHING A RARE DISEASE COUNCIL.

Be it enacted by the Senate and House of Representatives in General Assembly convened:

1 Section 1. (NEW) (*Effective July 1, 2022*) (a) There is established a
2 Connecticut Rare Disease Advisory Council. The council shall advise
3 and make recommendations to the Department of Public Health and
4 other state agencies, as appropriate, regarding the needs of persons in
5 the state living with a rare disease and such persons' caregivers. The
6 council may perform the following functions:

7 (1) Hold public hearings and otherwise make inquiries of and solicit
8 comments from the general public to assist with a study or survey of
9 persons living with a rare disease and such persons' caregivers and
10 health care providers;

11 (2) Consult with experts on rare diseases to develop policy
12 recommendations for improving patient access to quality medical care
13 in the state, affordable and comprehensive insurance coverage,
14 medications, medically necessary diagnostics, timely treatment and
15 other necessary services and therapies;

16 (3) Research and make recommendations to the department, other
17 state agencies, as necessary, and health carriers that provide services to
18 persons living with a rare disease regarding the adverse impact that
19 changes to health insurance coverage, drug formularies and utilization

20 review, as defined in section 38a-591a of the general statutes, may have
21 on the provision of treatment or care to persons living with a rare
22 disease;

23 (4) Research and identify priorities related to treatments and services
24 provided to persons living with a rare disease and develop policy
25 recommendations regarding (A) safeguards and legal protections
26 against discrimination and other practices that limit access to
27 appropriate health care, services or therapies, and (B) planning for
28 natural disasters and other public health emergencies;

29 (5) Research and make recommendations regarding improving the
30 quality and continuity of care for persons living with a rare disease who
31 are transitioning from pediatric to adult health care services;

32 (6) Research and make recommendations regarding the development
33 of educational materials on rare diseases, including, but not limited to,
34 online educational materials and a list of reliable resources for the
35 department, other state agencies, as necessary, the public, persons living
36 with a rare disease, such persons' families and caregivers, medical
37 school students and health care providers; and

38 (7) Research and make recommendations for support and training
39 resources for caregivers and health care providers of persons living with
40 a rare disease.

41 (b) The council shall consist of the following members, who shall live
42 and work in the state:

43 (1) The Commissioner of Public Health, or the commissioner's
44 designee;

45 (2) The Commissioner of Social Services, or the commissioner's
46 designee;

47 (3) The Insurance Commissioner, or the commissioner's designee,
48 who may be the representative of a health carrier;

49 (4) Two appointed by the Governor, one of whom shall be a
50 representative of an association of hospitals in the state or an
51 administrator of a hospital that provides health care to persons living
52 with a rare disease, and one of whom shall be a physician licensed under
53 chapter 370 of the general statutes who has expertise in the field of
54 medical genetics;

55 (5) Two appointed by the Senate chairperson of the joint standing
56 committee of the General Assembly having cognizance of matters
57 relating to public health, one of whom shall be a representative of a
58 patient advocacy group in the state representing all rare diseases, and
59 one of whom shall be the family member or caregiver of a pediatric
60 patient living with a rare disease;

61 (6) Two appointed by the House chairperson of the joint standing
62 committee of the General Assembly having cognizance of matters
63 relating to public health, one of whom shall be a representative of the
64 biopharmaceutical industry in the state who is involved in rare disease
65 research and therapy development, and one of whom shall be an adult
66 living with a rare disease;

67 (7) Two appointed by the Senate ranking member of the joint
68 standing committee of the General Assembly having cognizance of
69 matters relating to public health, one of whom shall be a member of the
70 scientific community in the state who is engaged in rare disease
71 research, and one of whom shall be the caregiver of a child or adult
72 living with a rare disease; and

73 (8) Two appointed by the House ranking member of the joint
74 standing committee of the General Assembly having cognizance of
75 matters relating to public health, one of whom shall be a physician
76 licensed to practice under chapter 370 of the general statutes who treats
77 persons living with a rare disease, and one of whom shall be a
78 representative, family member or caregiver of a person living with a rare
79 disease.

80 (c) All initial appointments to the council shall be made not later than
81 October 31, 2022. Any vacancy shall be filled by the appointing
82 authority. Except for members of the council who represent state
83 agencies, five of the members first appointed shall serve for a term of
84 two years, five of such members shall serve for a term of three years and,
85 thereafter, members shall serve for a term of two years. The
86 Commissioner of Public Health shall determine which of the members
87 first appointed shall serve for a term of two years and which of such
88 members shall serve for a term of three years. The members of the
89 council shall receive no compensation for their services but may be
90 reimbursed for any necessary expenses incurred in the performance of
91 their duties. The commissioner shall select an acting chairperson of the
92 council from its members for the purpose of organizing the first council
93 meeting. Such chairperson shall schedule and convene the first meeting,
94 which shall be held not later than November 30, 2022. The members of
95 the council shall appoint, by majority vote, a permanent chairperson
96 and vice-chairperson during the first meeting of the council. Nothing in
97 this subsection shall prohibit the reappointment of the chairperson,
98 vice-chairperson or any member of the council to their position on the
99 council.

100 (d) The council shall meet in person or on a remote platform not less
101 than six times between November 30, 2022, and October 31, 2023, as
102 determined by the chairperson. Thereafter, the council shall meet
103 quarterly in person or on a remote platform, as determined by the
104 chairperson.

105 (e) The council shall provide opportunities at council meetings for the
106 general public to make comments, hear updates from the council and
107 provide input on council activities. The council shall create an Internet
108 web site where meeting minutes, notices of upcoming meetings and
109 feedback may be posted.

110 (f) The council shall be within the Department of Public Health for
111 administrative purposes only.

112 (g) Not later than one year after the date of its first meeting, and
113 annually thereafter, the council shall report to the Governor and, in
114 accordance with the provisions of section 11-4a of the general statutes,
115 to the joint standing committee of the General Assembly having
116 cognizance of matters relating to public health regarding its findings
117 and recommendations, including, but not limited to, (1) the council's
118 activities, research findings and any recommendations for proposed
119 legislative changes, and (2) any potential sources of funding for the
120 council's activities, including, but not limited to, grants, donations,
121 sponsorships or in-kind donations.

This act shall take effect as follows and shall amend the following sections:		
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Section 1	July 1, 2022	New section
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Statement of Legislative Commissioners:

In Section 1, "section 38a-581" was changed to "section 38a-591a" for accuracy.

PH *Joint Favorable Subst. -LCO*